

Setting up a Hospice Service

The Experience of Hospice Casa Sperantei, Brasov, Romania
By Graham Perolls

Preface

Setting up a Hospice Service, by Graham Perolls, Founder and President of Hospice Casa Sperantei, Brasov, Romania, is one of a series of Fact Sheets published by **hospice information**. The series includes contributions from different hospices and palliative care services and echoes the basic principles of **hospice information** - to encourage sharing of information and experience within the worldwide hospice community.

While great care has been taken to ensure the accuracy of information contained in this Fact Sheet, **hospice information** assumes no responsibility for any errors or omissions. The views expressed in this Fact Sheet may not necessarily be those of Help the Hospices, nor of St Christopher's Hospice.

Acknowledgement

We should like to record our grateful thanks to Graham Perolls for making this paper available. The paper should not be reproduced without his permission. Any further enquiries, or comments, are welcomed and should be addressed to Graham Perolls, The Ellenor Foundation Romanian Hospice Appeal, 11a High Street, Otford, Kent TN14 5PG. Tel: (00 44) (0)1959 525110 Fax: + 525013 Email: ellenor@talk21.com

About hospice information

hospice information is a joint venture between St Christopher's Hospice and Help the Hospices. It brings together the experience and established reputation for high quality of the Hospice Information Service at St Christopher's and the national remit and innovative information developments of Help the Hospices.

Together we want to provide a world-class information service for health professionals and members of the public, on UK and international hospice and palliative care.

If you would like a list of all our Fact Sheets, or information about other activities of **hospice information**, please contact us at the address shown on the back cover. We welcome your comments and suggestions for further Fact Sheets.

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Phase 1 - The Vision

There is usually one person who has the initial “vision” for starting the project and who is the “driving force” behind it. We call him or her “The Founder”. What does such a person need?

1 Motivation

The Founder will usually either have a personal experience that motivates him/her (e.g. death of a family member/friend from cancer) or be a professional person (doctor, nurse, social worker etc.) who sees the need for such a service. The right motivation is important, but not enough in itself.

Personal note:

I became interested in hospice work when my father died from cancer in 1980 and he was cared for by St Christopher's Hospice in London. As a family, we experienced the transformation that good palliative care could achieve, and this inspired us to start a hospice in our local town of Dartford, named the Ellenor Foundation after our parents, Ellen and Norman. I had also visited Romania for the first time in 1975 as a tourist and made some friends in Brasov. After the “revolution” in 1989, I felt I could use my experience of establishing the Ellenor Foundation to help develop hospice care in Romania.

2 Commitment

The commitment needed to set up such a project is immense. The Founder must have the time - not just a couple of evenings a week and the odd time at week-ends - but the time to be able to attend meetings during the day over a considerable period of time. Perseverance and determination are essential qualities – a good project cannot be set up overnight.

Personal note:

I am fortunate enough to have my own business and can therefore take a considerable amount of time off from work without having to worry.

3 Personality

The Founder must have the right personality - the ability to get on well with people and express one's views clearly. He/she also needs to be a good listener. N.B. If you do not feel you are the right

person to lead the project, you can still be a valuable back-up person.

4 Credibility

The Founder must be able to convince people that he/she is capable of the task.

Previous management/leadership experience is obviously very helpful.

5 Finance

The first question you will be asked is “where is the money coming from”? It is a great advantage to start with some financial backing.

Personal Note:

Hospice Casa Sperantei was fortunate to start with the financial backing of the Ellenor Foundation, who launched a special Romanian Appeal.

6 Faith

Pioneering any project involves a step of faith. Pray for wisdom and guidance.

7 Good Advice

The Founder must be prepared to accept advice from the experts at every stage of the project. Cancer care is an emotive subject but emotive appeals may not succeed if they are not based on sound advice.

Personal note:

I lost count of the many people I asked advice from. I always found people in the hospice movement very willing to share their knowledge and experience. NB. The vision may begin with a group of people, in which case there will be a variety of talents, strengths, weaknesses etc. In this case it is very important to choose the right leader for the group.

Phase 2 - Sounding Out Period

Before taking any concrete steps it is vital to gain as much knowledge of the subject as possible. You will also need to spend time researching the needs of your own particular area. If you are based in Romania or other South Eastern European countries I would suggest that you start by contacting:

The Information Service at Hospice Casa Sperantei

c/o Princess Diana Centre for Palliative Medicine
Strada Piatra Mare 101. 2200 Brasov, Romania
Tel: +40 68 472415
Tel/Fax: +40 68 475433
E-mail: hospice@rdslink.ro
Centre Co-ordinator: Anca Pantea

The service will provide you with:

- a) details of any existing project in your area (it is important not to duplicate any service)
- b) details of hospice teams in the country and information about the Romanian National Association of Palliative Care – ANIP
- c) important statistics and facts (cancer deaths and current trends in care etc.) lots of other valuable information (advisers on hospice services, courses, training opportunities, useful publications etc.)
- d) access to a library with many palliative care books and journals, including Romanian publication - ABC of Palliative Medicine

There is also an International Information Service, **hospice information**, which publishes a list of hospice services in Central and Eastern Europe and all other parts of the world.

hospice information

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Avril Jackson, Ann Eve and Melanie Hodson
You will also benefit from visiting:

Existing hospices/home-care teams - At present there are very few hospice teams in South Eastern Europe, but this will change! Hospice Casa Sperantei will try to assist you as much as possible.

Local medical staff with an interest in terminal care - There may be a doctor or nurse in your community who has a particular interest -in caring for terminally ill patients and who would be a useful contact. He/she may be invaluable in helping to establish a service in your area.

Chief Nurse/Chief Doctor - It is essential to co-operate as much as possible with the senior medical personnel in your area.

Health Board - Ask for an informal meeting with the Director of the Health Board and advise them of your ideas. You may not have any firm proposals at this stage but let them know that you will contact them again when the steering

committee has completed its research.

When you feel well-prepared, it is time to form a steering committee.

Phase 3 - Steering Committee

Who should the steering committee consist of?

I would suggest a suitable combination of the following:

- Founder
- Local Family Doctor
- Health Board Member
- Senior Nurse
- Member of House of Insurance (or any other State Funding Body)
- Financial expert (bank manager, accountant etc)
- Representative from another hospice organisation
- Adviser of Terminal Care Services
- Member of Public with experience of hospice care (e.g. relative who has died, but not too recent bereavement)
- Member of Public with special interest in project

Personal note.

We had the Founder, a translator, a consultant oncologist, a music school professor, an American volunteer, a Health Board legal officer and a Northern Irish Nursing Director.

At the first meeting you will need to.

- Elect a Chairperson
- Ask the Founder to share his/her vision of the project
- Ask the Adviser or other suitable member to outline the history and philosophy of the hospice movement
- Ask the Health Board member or other suitable member to detail relevant facts and statistics for area (e.g. health authority population, local hospital facilities, number of cancer deaths, district nursing services available, etc)

- Report of discussions held during “sounding out” period
- Talk about the kind of service you want to provide
- Talk about the costs involved or set task to obtain these
- Talk about possible funding
- Possibly arrange visits to other hospice organisation
- Set tasks for individual members of the committee
- Think of a suitable name for the service
- Decide how regularly you need to meet

At subsequent meetings it will be necessary to discuss some of the above points in greater detail.

The following notes may be helpful:

Chairperson

This could be the Founder or another member of the steering committee

Adviser

Hospice Casa Sperantei will be pleased to recommend an adviser.

The Service

What kind of service is needed, taking into account local factors, existing services, geographical area etc.

What is your philosophy of care?

Will you offer symptom control advice to local hospitals as well as domiciliary care? What other staff will the service have?

- Medical Adviser/Director
- Nurses
- Social Worker
- Volunteer Organiser
- Administrator

- Secretary
- Any others

Where will the service be based?

Personal note.

Brasov has a population of approximately 70,000 with 1,000 deaths from cancer per year. We decided to start with domiciliary care and giving advice to staff in the local Oncology Hospital.

Funding

- What contribution will you ask the Health Authority for?
- What contribution can you expect from the House of Insurance?
- Can you find a partner hospice in another country?

Personal note.

We received an initial funding from the Ellenor Foundation but started fundraising in Romania after 3 years. The House of Insurance is still considering our application now that palliative care is recognised as a medical speciality in Romania. After 5 years we planned an Education Centre and after 8 years, an in-patient unit.

Costs

- Obtain costings from a number of existing services and get details from the local health

board about medical/nursing salaries. From this work out how much:

- each domiciliary nurse would cost approximately
- each medical session (half day) would cost approximately
- a full time secretary would cost approximately
- a typical service with one doctor and 3 full time nurses would cost approximately

Name

In choosing a name you may wish to.

- describe the service you are offering e.g. DEVA HOSPICE, ECHIPA HOSPICE "Mihai Eminescu"
- add a personal touch e.g. Hospice Ciprian after a patient/relative who died.

Phase 4 - Formation and Launch of Charity

When the Health Board has agreed to the establishment of the service and you have obtained the necessary agreements/funding arrangements etc., it is time to register as an Association.

1 Legal

You will need to employ a good solicitor who is experienced in dealing with this kind of service. He will prepare a Memorandum and Articles of Association. It is a good idea to obtain copies of the Memoranda and Articles of Association of other hospice organisations.

N.B. Expert legal advice is essential.

Board of Directors (Council of Management)

You will need to appoint directors of the charitable company (usually referred to as Members of Council) and a Secretary. During the steering committee stage you will have had a chance to assess the suitability and commitment of steering committee members. The first directors will usually be chosen from the steering committee members, but make sure you do not include anyone who has proved unsuitable or uncommitted, however difficult this may be. (You will save a lot of problems later).

Personal note:

We decided to start with 7 directors and a secretary, as we felt this was a workable number. Four directors were original steering committee members and we elected 3 new ones.

The purpose of a Council of Management is to ensure that the charitable objectives of the Foundation are achieved. This includes overseeing the management of the organisation, supporting the staff and dealing with problems, making decisions on company policy and ensuring that there is adequate funding for the service.

2 Publicity

This is the right time to start your publicity campaign. Try to establish good relationships with the editors of your local newspapers. They can be tremendously helpful if they are co-operative, but can also prove a hindrance. Contact your local

radio stations and editors of local magazines/church newsletters etc. Supply the above with comprehensive "press releases" and encourage reporters to attend functions.

Personal note:

We found that the media had some difficulty in grasping the concept of a hospice service, and printed some inaccurate articles.

It is helpful to have a publicity officer with experience, but this is not always possible. You will also need publicity material in the form of a brochure/handout, which may have a tear-off slip for those wishing to make donations or help in other ways.

3 The Official Launch

This is an opportunity to make a real impact on the local community, and should be well prepared and organised.

- Fix a date – leave plenty of time for preparation
- Book a suitable location
- Consider inviting a Guest Speaker
- Decide who should be invited.

Suggestions:

Health Board members and key personnel, Local Medical Personnel, Family Doctors Consultants, District Nurses, Senior Nurses, Social Workers, Physio and Occupational Therapists, Pharmacists, Representatives of Local Voluntary Organisations/Clubs/Churches etc, Well-known local personalities (Mayor, Member of Parliament etc) Local Business People, Interested Members of the Public

- Choose a skilful Chairman
- Obtain a sponsor (e.g. Drug Company/Local Council)

Phase 5 - Final Preparations

Recruitment of Staff

- Prepare job descriptions and place advertisements
- Personal note: We obtained a number of job descriptions from other hospices. We placed advertisements in Medical Journals and local newspapers.
- Appoint an interview panel
Personal note: Our panel consisted of: Director, Chief Nurse and Chief Doctor.
- Recruit staff
Personal note: It is so important to start with the right staff. We needed to advertise and interview four times before we found the nursing staff we were looking for.

Preparation of base

- set up office
- obtain necessary equipment (files, typewriter etc)
- prepare accounting system
- co-ordinate fundraising policies

Seminars

It is helpful to organise seminars for local medical staff at an early stage (e.g. symptom control, the role of the hospice care team) to promote interest in the new service.

Training

If your nurses have not completed a palliative care diploma course (details from **hospice information**) try to book a place as soon as possible.

When all the groundwork is complete, and suitable staff have been recruited, it is time to start the service.

Personal note:

When our nurses took up post we arranged a comprehensive orientation programme. They met local family doctors, nurses etc and visited local hospitals. They also had some training in a UK hospice. This kind of groundwork is vital to the success of the service.

...To find out more about opportunities for visits and clinical placements in UK hospices contact **hospice information** (see page 2 for address etc.)

Phase 6 - Operational Policy for Hospice Casa Sperantei

Philosophy of Care

Hospice care recognises that dying is a normal process, and that for the dying person the last phase of their life is a special time for integration and reconciliation. It recognises the need for dying people to live fully with dignity and comfort until they die, and neither precipitates nor postpones death. Finally, it provides ongoing support for bereaved families and friends.

Hospice Casa Sperantei works with the medical and nursing staff employed in the community and hospitals to facilitate the provision of hospice care for the people of Brasov. The underlying philosophy of the organisation is based on Christian principles. Importance is attached to spiritual and emotional wellbeing of all patients and their families in a context which respects the individual's beliefs and practices.

The services provided by Hospice Casa Sperantei are free of charge to patients and families.

The Management Team

The Management Team consists of an Executive Director, a Senior Nurse Manager, an accountant and a fund-raiser. These are answerable to the Council of Management. There is a regular weekly meeting of the management team with the whole team. The management team members present reports on a bi-monthly basis to the Council of Management.

There is a monthly business meeting with the staff to present new management initiatives and discuss any problems which have arisen.

The Home Care Team

The Home Care Team consists of eight full-time nurses and a Nurse Manager.

The Primary Nursing model is used. Each patient is allocated a key nurse who oversees their care and is responsible for liaising with the Primary Health Care Team or hospital staff. Several team members will visit each patient but the primary nurse is accountable for the planning and management of care.

The whole team meets daily with the Medical Director to discuss aspects of patient care.

The Senior Nurse provides job and performance reviews for all the nursing staff on a two-monthly basis. Training needs are identified at these reviews and are met by individual tuition, secondment to training courses, and in-service training sessions.

The Medical Team

A Medical Director and 2 hospice doctors provide medical support for the nursing staff. They are responsible for overseeing the medical aspects of care of both home-care and hospital patients and liaising with family doctors and hospital consultants. The medical team visits patients where this is necessary, and supervision of the care of all patients is provided through the team meeting and the regular meetings with the primary nurses. The doctors also provide educational input to the team as well as undertaking other training commitments.

The Paediatric Team

This consists of a paediatrician and two paediatric

nurses.

Secretarial Support

Part of the role of the full-time secretary in the office is to receive calls and administer correspondence on behalf of the clinical team.

Chaplain

The Team has two honorary Chaplains – an orthodox priest and a Baptist pastor – who offer spiritual and pastoral support to team members and liaise with other local clergymen as appropriate. They meet with the team twice a month and can also be contacted on an individual basis.

The Volunteer Service

Volunteers are encouraged to be involved in fundraising. Certain volunteers are also involved in patient care.

Referral Policy

Hospice Casa Sperantei accepts referrals of patients who generally are in the later stages of chronic progressive illnesses and who live in Brasov and the surrounding area. However, referrals are always considered on an individual basis and other patients may be accepted at the joint discretion of the Nurse Manager and Medical Director.

Home Care referrals are accepted preferably with the knowledge and approval of the patient's family doctor or hospital consultant.

A primary nurse is allocated to each patient at the time of referral and contact is made with the patient and family as soon as possible to arrange a first visit. After this visit the primary nurse presents the patient details to the full clinical team at the next team meeting and a management plan for the patient is discussed at this meeting with input from the doctors. Where it becomes apparent at the initial visit that there are urgent medical or social problems, a doctor or volunteer is organised to follow up as soon as possible. In some circumstances it may be apparent from the information at the time of referral that a medical opinion is of paramount importance and then a doctor rather than the primary nurse perform the first visit. Occasionally referrals are made solely to the doctors for a medical opinion and "one-off" visits are made to such patients.

After the initial visit patients are then contacted

according to need, and the frequency of visits and phone calls is reviewed after each patient contact. This means that patients may be visited as often as twice a day or as infrequently as once a fortnight. Where appropriate, telephone calls are used to supplement visits. Visits to patients are provisionally planned ahead on a weekly basis with a readiness to respond to changing needs as they arise. Patients and/or their families may also be seen at the Oncology, Paediatric or other hospitals in Brasov.

Regular contact is also made with a patient's family doctor using personal visits, telephone calls and summary letters. The frequency of family doctor contact for each patient is recorded and monitored at each primary nurse's meeting with the Senior Nurse and Medical Director. Each hospital consultant concerned with the care of a patient is informed of the involvement of the hospice and further information about their medical condition is requested.

Hospital referrals are taken from nursing or medical staff on the wards, provided the consultant concerned approves of this course of action.

Where Home Care patients are admitted to hospital, permission of the ward nursing staff is obtained prior to the hospice team visiting a patient.

Patient Records

Confidential medical and nursing notes are kept in the office and signed entries are made after every patient, relative or professional contact. These notes are reviewed at each primary nurse's meeting with the senior nurse and medical director. There is a central diary held in the office where all messages about patients are recorded and a record is kept of visits and phone calls undertaken each day.

Weekends

Hospice Casa Sperantei provides a weekend service for patients and their carers. The nurses work a 1 in 6 rota and visit patients as requested. Medical support is always available. The nurse on call and the supporting doctor always carry a mobile phone.

Social Help

For extremely poor patients a small fund operates

to provide essential items such as basic foods.

The Bereavement Service

The Senior Nurse is responsible for co-ordinating a bereavement service. This is initially provided by the primary nurse, with referral to a volunteer as appropriate.

Drugs

Patients normally receive prescriptions from their own Family Doctor. However due to frequent unavailability of drugs a limited supply of relevant drugs is kept in the hospice pharmacy and supplied to the patient free of charge.

Equipment

Hospice Casa Sperantei owns a variety of aids and appliances, which are available for loan to patients. There is a regular review of equipment and also new items are purchased to meet patients' individual needs.

Education

The philosophy of hospice organisations incorporates the importance of sharing the principles of hospice care with all other relevant agencies. Educational commitments are undertaken for nurses, family doctors, hospital doctors and representatives of Social Services and Voluntary Organisations. This includes formal lectures, seminar sessions and individual tuition as well as practical secondments to the team. Contact the Education Centre in Brasov for details.

F4 Setting up a Hospice Service

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